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Supported decision making - experiences, approaches and preferences

Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., McLaughlin, A., Montgomery, L., Mulvenna, C., Norris, B., Owens, A., Irvine, R. A. S., & Webb, P. (2018). *Supported decision making - experiences, approaches and preferences*.

Document Version:

Publisher's PDF, also known as Version of record

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Supported decision making - experiences, approaches and preferences

June 2018



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Acknowledgements

This research was funded as part of the Disability Research on Independent Living & Learning (DRILL) Programme. DRILL was fully funded by the Big Lottery Fund and delivered in partnership by Disability Action, Disability Rights UK, Disability Wales and Inclusion Scotland. The DRILL Programme was led by disabled people and funded coproduced research and pilot projects focused on exploring how disabled people can live as full citizens and take part socially, economically and politically.

The research project was led by Praxis Care in partnership with Mencap NI and Queen's University Belfast and so the support of these three organisations is also acknowledged. The project was informed at key points throughout the research process by an International Advisory Group which included specialist disabled and non-disabled researchers with expertise in this area. Advisory group members advised on issues such as the existing research, the interview schedule, data analysis and dissemination.

The Advisory Group members were:

- Taryn McKeen, Mental Health and Capacity Unit, Department of Health (previously Tomas Adell, Mental Health and Capacity Unit, Department of Health)
- Keith Lynch, People First Scotland (who had recently completed directly relevant research in Scotland about supported decision making)
- Margaret Kelly, Director of Mencap NI
- Dr Nancy Hansen, Director of the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba
- Professor Michael Schwartz, Director of the Disability Rights Clinic in the Office of Clinical Legal Education at Syracuse University College of Law, in New York State, where he supervises students in disability advocacy and teaches clinical skills and disability law
- Associate Professor Lisa Brophy, from the Centre for Mental Health, Melbourne School of Population and Global Health, University of Melbourne and is also Mind Australia's Principal Research Fellow
- Professor Richard O'Reilly, a Professor of Psychiatry at Western University in London, Ontario and at the Northern Ontario School of Medicine. Professor O'Reilly has researched extensively in the area of mental health law
- Dr Anna Arstein-Kerslake, Senior Lecturer, Melbourne Law School and Convenor of the Disability Research Initiative, University of Melbourne

Finally, the research team would like to thank all the participants who agreed to be interviewed and provided their perspective on supported decision making. The participants were also invited to consider the draft findings and provided further input on the analysis and recommendations.

This report can be referenced as:

Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., McLaughlin, A., Montgomery, L., Mulvenna, C., Norris, B., Owens, A., Shea Irvine, R. and Webb, P. (2018) *Supported decision making - experiences, approaches and preferences*. Belfast: Praxis Care, Mencap and Queen's University Belfast.

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Executive Summary

This report presents the findings from a research project which explored how people have, or have not been, supported to make their own decisions. It was funded by Disability Research on Independent Living and Learning (DRILL) and used a coproduction approach between disabled people, Praxis Care, Mencap NI and Queen's University Belfast.

The project involved peer researchers interviewing 41 people with mental health problems and/or intellectual disabilities to gain an in-depth understanding of their experiences of support for decision making and their preferences and ideas for how decision making should be supported in the future. The project therefore provides an overview of experiences of support as well as identifying the supports which work for them. It is intended that this will inform how the new support principle in the Mental Capacity Act (Northern Ireland) 2016 should be implemented in practice.

The key findings include:

- Decision making is a central aspect of people's lives. Participants discussed the positive role which decision making can have in their life but also how it felt when they are not supported to make their own decisions.
- Participants said there were three things that make decision making harder: the type of decision; the role of other people; and what the outcome might be.
- Time was consistently identified as a very important factor in making decisions.
- In terms of support, people said they would like: practical support including more accessible information; emotional support including someone to talk to; and sometimes the options to choose from.
- The peer researcher aspect of the project strengthened the research process and was valued by participants. This is an evolving area of research practice that needs further critical exploration of the issues involved.





The main recommendations are for how, in general, support for decision making should be provided but also specifically for how these findings might help to inform the Code of Practice which will provide important guidance on how people should be supported:

- Support for decision making needs to be individualised. The support needed depends on a wide range of factors including: the relevant information and how that can be communicated; the type of decision needed; who else is involved; what the possible options are; and what the outcome might be. The support needed will therefore vary across decisions, time and people so the support principle should be understood in a broad and flexible sense to reflect this variation and complexity.
- There was very little mention of existing, more formal processes of support such as advance decisions, crisis care planning and Enduring Power of Attorney. The new Act will introduce a positive, more comprehensive framework for these more formal processes but considerable efforts may be needed to promote public awareness and understanding of what these involve.
- Time was consistently identified as an important factor and it should be emphasised that if there is urgency to make a decision, what the cause of the urgency is and whether more time could be available.
- There are already a number of excellent sources for guidance for supported decision making, as highlighted in this report, and these international exemplars should help inform the operationalisation of the support principle.
- Although much of this project focused on the positive potential of support, the limitations and potential complexities of support should also be explicitly considered in the Code of Practice. Participants acknowledged that, in some circumstances, regardless of the support provided, it may be necessary for someone else to make the relevant decision. It should also be highlighted that what is intended to be support may, at times, move into undue influence, coercion and/or abuse.
- Participants highlighted that they bring considerable experience of support and were open to being further involved in discussing these issues. The Code of Practice will be open to public consultation and meetings, such as the participant event for this project, could be a very useful aspect of that consultation process.
- Although there was great support for support, and positive accounts of when people felt supported, there is little evidence for what interventions work for whom in what circumstances. There is an immediate need for research evidence on the effectiveness of the wide range of support interventions.

Introduction

Making decisions about your own life is a key aspect of independence, freedom and human rights. Mental health law has previously allowed compulsory intervention even when a person has the decision making ability to refuse intervention. This discriminates against those with mental health problems and intellectual disabilities. In May 2016 the Mental Capacity Act (Northern Ireland) became statute law although it may not be implemented until 2020/21. In contrast to other countries this law will replace, rather than be in parallel to, mental health law. This is a unique and progressive development which seeks to address the discrimination of separate mental health law. A core principle of the new Act is that people are “not to be treated as unable to make a decision... unless all practicable help and support to enable the person to make a decision about the matter have been given without success” (Article 1(4)). This research project was therefore designed to explore how people with mental health and/or learning disabilities¹ have, or have not been, supported to make their own decisions. It also asked participants what works for them and sought their ideas on how people with mental health and/or learning disabilities should be supported to make decisions. The overall aim of the research is to inform how the new support principle should be implemented in practice.

What is Supported Decision Making

“Supported decision-making is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control” (Carter, 2009, p. 9). Carter (2009, p.8) also refers to the United Nations Handbook on the Convention on Rights of Persons with Disabilities, which states: “Supported decision-making can take many forms. Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone

capable of exercising his/her legal capacity”. A further definition of supported decision making has been provided by the Victorian Law Reform Commission (2011, p.19), namely “An approach to decision making that involves providing a person with impaired capacity the support they need to make their own decision. It is often contrasted with substitute decision making, where a decision is made on behalf of a person who is unable to make that decision”.

What is the research issue?

There are people who, without support, would be assessed as incapable of making certain decisions but with the appropriate support are capable of making those decisions and so to not provide that support infringes their rights, undermines their autonomy and reinforces their exclusion from society.

Supported decision making should be considered as an important part of a continuum of decision making from autonomous decision making through to substitute decision making. Law and policy have tended to focus on either end of the spectrum and have approached capacity as if people are either globally capable or incapable, but most people require some level of support with decision making. The Mental Capacity Act (Northern Ireland) 2016 offers an excellent opportunity to create this comprehensive legal and policy framework.

There is very limited research evidence available about disabled people’s experiences of the range of approaches provided to support decision-making; what approaches work for whom; and what people’s preferences are for support. This evidence is urgently needed to inform the Code of Practice for the new Act and the wider implementation process.

The need for supported decision making

There are a number of rights based, effectiveness and pragmatic arguments for providing supported decision making. The United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) requires States to “take appropriate measures to

¹ Intellectual disability is the more internationally recognised term but learning disability is still more commonly used in Northern Ireland and was the preferred term of the peer researchers involved in the project.

provide access by persons with disabilities to the support they may require in exercising their legal capacity” (Article 12(3)). Article 12(3) is the key reference to supported decision making, but the whole of Article 12 represents a paradigm shift away from the focus of policy and law being only on substitute decision making for people who are assessed as lacking the capacity to make a decision. The article requires the development of a positive range of supports to enable people to fully exercise their rights and, wherever possible, prevent the need for substitute decision making (Quinn, 2010).

The central principle underlying supported decision making is autonomy, that “no person should have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support” (Chartres and Brayley, 2010, p. 1).

The effectiveness arguments focus more on the benefits that supported decision making provides for individuals, families and societies. Chartres and Brayley (2010) suggest that supported decision making has three broad benefits. First, it can support personal autonomy, authority and control that people have over their own lives. Second, it can provide a clearer structure for individuals and families negotiating and making decisions and plans in the context of family, friends, informal carers and services. Third, they suggest that it can provide a more comprehensive means of ensuring people’s legal and personal capacity to make decisions is promoted and respected. Chartres and Brayley (2010, p.32) go on to list the potential benefits for a person with disabilities as: “citizenship, personal empowerment; self-determination; self-esteem; respect for decisions; control over their lives; confidence in decision making; confidence in rights; development of decision making skills and capacity; increase in areas of decision making; and increase in support networks”.

The process of developing and implementing supported decision making will also provide societal benefits. Some of the dangers of not respecting people’s rights to be fully included in society and not supporting people to make their own decisions have been demonstrated through research on institutionalisation and repeated

inquiries into the abuse of people in care. The benefits to society of supported decision making include: contributing to a better and wider understanding of the importance of respecting the rights of all citizens; a more inclusive approach to disability policy and support; and generally enabling better decisions to be made.

The last benefit to society overlaps with the pragmatic arguments for supported decision making. These are based on the procedural justice research in mental health services which suggests that, in an assessment process, if people are listened to, respected and feel that their views are being considered, even if they do not agree with the outcome of that process, they are less likely to feel coerced and dissatisfied (McKenna et al., 2000; Galon and Wineman, 2010). In general terms, it seems reasonable to assume that if a person has received the support necessary to make their own decision, such as the type of service to use, they may be more willing to fully engage and benefit from that service.



Overview of the structure of the report

The next section of the report provides a review of the relevant literature on supported decision making. This includes an examination of the concept of supported decision making and a summary of the main approaches or models. The existing research on people's experiences of support is also reviewed and a number of case studies of how supported decision making has been implemented in other jurisdictions are provided.

Following the literature review, some of the existing guidance on supported decision making is outlined. This includes examples which have been developed based on specific research studies as well as national level law and policy implementation guidance.

The methodology of the research is then presented. This was a qualitative study and a core element of the methodology was the recruitment of 4 peer researchers to be involved in all aspects of the study. Peer researchers were required to

have experienced (past or current) mental health problems and/or to have a learning disability. Peer researchers were recruited via Praxis Care and Mencap NI in September 2017 and were employed by these organisations for the duration of the study (September 17 – June 2018).

The role of the peer researchers was central to the research project. The researchers from Praxis Care and Mencap NI provided expertise on the current issues relating to how decisions were supported, or indeed not supported, in mental health and learning disability services. This informed the development of the interview questions. They interviewed participants (supported by a member of the wider research team); were involved in the analysis of the data; disseminated the preliminary research findings at the KESS seminar; and contributed to the writing up of the final report and other dissemination activities.

The final two sections of the report are the discussion, which considers the findings of the research in the context of the wider literature, and the conclusion which provides specific suggestions for how the support principle can and should be implemented.



Literature review

In 2015, a review of the international literature published between 2000 and 2011 related to supported decision making identified four main themes within the studies: stakeholders' views on supported decision making; barriers to the implementation of supported decision making; ways to improve implementation; and the impact of supported decision making (Davidson et al., 2015). Since 2015, there have been further developments in research and policy relating to supported decision making. This literature review, therefore, aims to highlight the research advancements and reflect the evolving conceptualization and practice of supported decision making.

A literature search, which included a manual search of relevant journals and a Google search for grey literature, was conducted and a Rapid Evidence Assessment method was used to analyse the results. Rapid Evidence Assessments provide a synthesis that is more robust than narrative analysis but less structured than systematic reviews (Government Research Service, 2010). Key search terms used to identify the relevant materials included: decision making; legal capacity; guardianship; intellectual disability; mental disability; psychosocial disability; and mental health. The search returned many academic sources and project reports and the most relevant have been included in this literature review.

This report aims to update Davidson et al.'s international literature review (2015) in light of two significant developments related to supported decision making in Northern Ireland: the introduction of the Mental Capacity Act (Northern Ireland) 2016 and the United Nations Committee on the Rights of Persons with Disabilities Concluding Observations made to the United Kingdom in 2017. Recognizing that these two documents provide an opportunity to advance the discussion about how supported decision making can be implemented in Northern Ireland, this report is divided into three sections: 1. Conceptualizing supported decision making; 2. Approaches to supported decision making; and 3. Experiences of supported decision making.

Conceptualizing Supported Decision Making

As mentioned in the introduction, the Victorian Law Reform Commission defines supported decision making as an “approach to decision making that involves providing a person with impaired capacity the support they need to make their own decision” (2011, p. 19). Similarly, the Mental Disability Advocacy Council defines supported decision making as the “alternative to guardianship... premised on the fact that with proper support, a person who would otherwise be deemed to lack capacity is, in fact, able to make personal decisions” (Carter, 2009, p. 8). Supported decision making provides an alternative to the substitute decision making in which decisions are made by a third-party, “who generally base decisions on the perceived objective best interests of the person” (Flynn & Arnstein-Kerslake, 2014). It is based on the belief that “every human being is communicating all the time and that this communication will include preferences” (Beamer & Brookes, 2001, p.4). It is, therefore, the way in which these preferences are interpreted and implemented that matters, rather than an assumption of the capacity of the individual (ibid). Supported decision making may require the assistance of a trusted supporter to communicate the individual's preferences or to help them understand the choices and consequences (United Nations, 2006). It can occur through formal arrangements, such as during legal processes, or through less formal arrangements, where a friend or colleague may help an individual make decisions about daily life (Gooding, 2012).

The recognition of decision making as a critical component of personhood and citizenship is also important for the realization of equal rights (Bach & Kerzner, 2010; Flynn & Arnstein-Kerslake, 2014). As such, Professor Amita Dhandra suggested that “supported decision making would be better conceived as a universal component of community life for all citizens, rather than something targeting only those with a disability” (Carney, 2017, p. 49). This statement is an acknowledgement that all people need some level of support in making decisions some of the time.

Supported Decision Making in the Convention on the Rights of Persons with Disabilities

Supported decision making is recognized in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in Article 12 - Equal recognition before the law which states:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective
5. safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.



It has been argued that Article 12 is not only a shift away from a preference for substitute decision making, but that it requires the development of a range of support options to enable people to exercise their rights and prevent the need for substitute decision making to the greatest extent possible (Quinn, 2010; Devi, Bickenbach & Stucki, 2011). It is also moving away from the “traditional” approach where a person may be deemed incapable based solely on the fact that they have an impairment, toward a “functional test”, by which a person is “considered incapable, if, by reason of the disability, he or she is unable to perform a specific task” (Devi, Bickenbach & Stucki, 2011, p. 253). The support for Article 12, however, has been far from universal; with declarations made by Australia, Egypt, Estonia, France, Georgia, Netherlands, Norway, Poland, Singapore, Syria, UK, and Venezuela in their ratification of the CRPD. Some of the major stumbling blocks include guardianship legislation and practices and concerns around safeguarding.

In order to address the concerns regarding the implementation of Article 12, the UN Committee on the Rights of Persons with Disabilities released General Comment No. 1 (2014) to clarify how they intended to interpret Article 12 when examining states’ compliance. With regard to 12.3 on support, it stated:

States parties must refrain from denying persons with disabilities their legal capacity and must, rather, provide persons with disabilities access to the support necessary to enable them to make decisions that have legal effect. Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision making... “Support” is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication... Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and

preferences. For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others (para. 16-17).

To address concerns around safeguarding, the Committee stated, [Article 12, paragraph 4] requires States parties to create appropriate and effective safeguards for the exercise of legal capacity. The primary purpose of these safeguards must be to ensure the respect of the person’s rights, will and preferences... Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the “best interpretation of will and preferences” must replace the “best interests” determinations... The “best interests” principle is not a safeguard which complies with article 12 in relation to adults... safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes (para. 20-22).

The interpretation of Article 12 has been the subject of many academic analyses regarding legal capacity (Devi, Bickenbach & Stucki, 2011; Morrissey, 2012; Devi, 2013; Dawson, 2015; de Bhailis & Flynn, 2017; Arstein-Kerslake & Flynn, 2017). Arstein-Kerslake & Flynn (2017), however, argue that while many legal scholars have written about when to recognise legal agency, fewer have addressed how to protect it without establishing a mental capacity threshold or how the exercise of legal agency is understood. Taking a critical approach to the recommendations made in General Comment No. 1, Dawson (2015) argues that a more conservative approach to interpreting Article 12 that allows for the recognition of the concept of mental capacity and substitute decision making or involuntary treatment (as long as strong safeguards are put in place to ensure that it is used only in exceptional circumstances) would be “more likely to generate positive responses from state parties in terms of law reform” (p. 70). Similarly, Parker (2016) also takes a critical approach to General Comment No. 1 and “advises a more incremental development of existing guardianship regimes” (p. 381). He argues that this is to provide a “more realistic balance between neglecting the real limits of those with

mental disabilities and thereby ignoring their identity and particularity, and continuing to bring them equally and fully into society” (p. 381). Finally, Carney concludes that a “pure repeal of proxy decision-making on its own is not viable in realpolitik terms so progressive realisation of ‘repeal with adequate support’ must instead be devised for [supported decision making] implementation to progress” (2017, p. 1).

In 2017, the United Kingdom underwent an examination by the Committee on the Rights of Persons with Disabilities regarding their compliance of the CRPD in which the Committee recommended that the UK “abolish all forms of substitute decision-making” and introduce new legislation pertaining to mental capacity and mental health that is in-line with the CRPD. It also recommended that more research, data, and examples of good practice be collected to develop supported decision making programmes (UN Committee on the Rights of Persons with Disabilities, 2017, p. 7). These findings, which will require annual progress updates to the Committee by the State party, are an important recognition of the value placed on supported decision making and legal capacity in realizing the full implementation of the UN Convention on the Rights of Persons with Disabilities.

Approaches to Supported Decision Making

Although the key components of empowerment, choice and control are necessary to facilitate supported decision making (Carter, 2009), the ways in which it can be implemented vary. Grounded in the principles of person-centredness (recognizing the will and preferences of the individual) and dealing with the provision of clear information in order to simplify the decision-making process (Wong et al., 2000; Robertson et al., 2005; Dowling et al., 2007; Carter, 2009; Flynn & Arstein-Kerslake, 2014), supported decision making may include independent advocacy or supportive networks of friends and family. It is most commonly provided on a voluntary basis by someone with whom the individual has a long-term relationship based on trust and may have an outcome that is verbal or written (Carter, 2009). Supports may include assisting the individual in: formulating an opinion; considering a range of choices and making a selection; engaging in a

decision-making process with other parties; and taking action to implement a decision (Bach & Kerzner, 2010). The following section will highlight some of the proposed models/approaches for putting supported decision making into practice.

Models of / Approaches to Supported Decision Making Adapted Stepped Model

The Adapted Stepped Model (Carney, 2014) was based on the Stepped Model proposed by Brayley at the World Congress of Adult Guardianship in October 2012 in Melbourne. This model has three distinct features: (1) it is “relationship driven” support in which the individual remains in control at all times; (2) it makes a distinction between “assistance” and “support”; and (3) it allows for external monitoring of the “relationship of support”.

Bach & Kerzner’s Model

Bach and Kerzner, working in Ontario, identify three main types of support in exercising supported decision making: (1) supports to explore choices and come to a decision; (2) supports to engage with others in decision-making and come to an agreement; and (3) supports to enact a decision once it has been made (2010, p. 73). They also argue that legal capacity is exercised in different ways depending on an individual’s decision-making abilities, communication support needs, and whether at least one other person can reasonably understand and communicate the person’s will and/or intention. Finally, they acknowledge the relationship between decision-making abilities, supports and accommodations, and recognition of status that enable people to move along a continuum of support (from substitute decision-making to supported decision-making) as skills, supports, and accommodations develop and are recognized.

Flynn & Arstein-Kerslake’s Model

Flynn & Arstein-Kerslake propose to build on Bach & Kerzner’s continuum of supports by suggesting that “the enabling conditions must be provided at all times – even if these do not result in a perceptible increase in decision-making capability for the individual concerned” (Flynn & Arstein-Kerslake, 2014, pp. 96-97). They recognize enabling conditions as including advocacy,

reasonable accommodations, accessible information and communication, recognition of different forms of expression, and advance planning tools, and argue that the presence of enabling conditions can allow an individual to move along the continuum of support.

Legal Mentor Model

The Legal Mentor Model (also known as the ‘God Man’ model) provides an alternative to guardianship and is most notably used in Sweden. It allows for a “mentor”, appointed through local court proceedings with the consent of the individual to be supported, to act on behalf of the individual for as long as the individual deems the mentorship to be beneficial. The mentor may be anyone that the individual trusts (close family members, friend, social worker, lawyer, etc.) and the procedure is swift (approximately three weeks) with no application or court fees. The Legal Mentor Model enables the mentor to represent the individual in applying for social services or financial or legal matters without compromising their legal capacity. The largest barrier to implementation in Sweden has been a lack of available mentors to meet the demand (Devi, Birkenbach & Stucki, 2011).

Open Dialogues Model

The Open Dialogues Model draws upon forum meetings in which an entire family or social network may contribute to assisting the individual in decision making. The decision is made in the presence of all members. The model, developed in Finland, aims to ‘gather information about the problem; to build a treatment plan and to generate a psychotherapeutic dialogue’ (Morrissey, 2012, p. 435).

Peer Support Model

The Peer Support Model connects people that have had similar experiences to discuss the process and help support decision making. The approach allows for the individual and the peer supporter to engage in conversation ‘without a predetermined outcome’ (Morrissey, 2012, p. 438). Studies have also shown that peer support may contribute to more successful outcomes and competition of programmes (Morrissey, 2012).

PO-Skane Model

The PO-Skane Model is primarily focused on supported decision making for adults with psychosocial disabilities and was developed in Sweden. The model utilises Personal Ombudsmen (POs) who do not have connections to social services, psychiatry, or the individual’s family to assist an individual in decision making. The PO is paid by NGOs to assist in the implementation of what the individual has decided on a range of topics: they do not make decisions on behalf of the individual or act in the “best interest” of the individual. The relationship between the PO and the individual usually develops over several years (Morrissey, 2012).

Representation Agreement

A representation agreement enables a trusted person or support service to assist an individual to make or communicate a decision. It is rooted in the belief that most people make significant decisions in consultation with friends and family and that people with disabilities should not be treated differently. Under this approach, the individual does not give up any existing legal capacity upon entering into a representation agreement and capacity of the individual to make decisions is assumed. An additional benefit of this approach is that it “formalises informal decision-making” (Morrissey, 2012, p. 434). Some current examples of this approach (namely the British Columbia Representation Agreement Act) does still allow decisions to be made on the person’s behalf (Devi, Birkenbach & Stucki, 2011).

Supported Decision Making in Practice

The recent introduction of the Mental Capacity (Northern Ireland) Act 2016 and the ongoing development of the Code of Practice encourages an exploration of how other jurisdictions have addressed supported decision making initiatives.

England & Wales

In England and Wales, the Mental Capacity Act 2005 Code of Practice (Department for Constitutional Affairs, 2007, Chapter 3) provides guidance on supported decision making. It suggests that people should be helped to make their own decisions by ensuring that they are provided with relevant information,

communication is conducted in an appropriate way, and that the person is made to feel at ease and supported. The National Institute for Health and Care Excellence (NICE) is currently developing guidance for decision-making and mental capacity to help health and social care practitioners in England and is expected to be published in June 2018.

Ireland

Ireland's Assisted Decision-Making (Capacity) Act 2015 breaks from traditional views of capacity to consider the uniqueness of each decision with relation to topic, time, and place. It states, 'a person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time' (S3(1)). The 2015 Act allows for the individual whose decision-making capabilities may be in question to appoint someone they trust to support them to make decisions related to their well-being, property, or finances. The subsequent guidance produced for Health and Social Care Professionals (2017) stated that although people may require different amounts of assistance to make particular decisions, 'it must always be presumed that a person has capacity to make a decision, regardless of the presence of [intellectual or physical disability, cognitive difficulties due, for example, to acquired brain injury or dementia, and people with mental health problems]' (Health Service Executive, 2017, p.11). It also argued that the 2015 Act affects 'everyone working in health (physical or mental health) and social care, including those working in statutory, voluntary, community and privately funded organizations' (Health Service Executive, 2017, p. 10).

Canada

Canada is considered to be one of the leading countries in the legal implementation of supported decision making (Devi, Birkenbach & Stucki, 2010, p.255). This is owing to the devolved nature of capacity legislation occurring at the province and territory levels. The following provides a brief overview of some of the approaches.

Alberta - Legislation introduced in 2009 provides

'legal mechanisms for individuals to appoint people to make decisions for them, appoint people to assist them to make decisions, as well as allowing a court to appoint a co-decision-maker, guardian or trustee' (Kerzner, 2011, p. 33). While these options present a spectrum of decision making support options, they only cover personal, non-financial decisions. Kerzner also argues that the complexity and confusing nature of the different methods for creating substitute or supported decision making agreements may limit their use (2011, p. 35).

British Columbia – The Representation Agreement Act (RAA) in British Columbia – is frequently cited as a successful supported decision making model (Devi, Birkenbach & Stucki, 2010; Morrissey, 2012). The RAA enables an adult to enter into a 'representation agreement' with a trusted person or support agency who is then able to legally assist that individual in making and communicating decisions or to make decisions on their behalf (but only as a last resort) (Devi, Birkenbach & Stucki, 2010, p.255). It acknowledges a spectrum of decision making capacity and sets out four factors that must be taken into account when making a decision: (1) communicating a desire to have someone assist in decision making; (2) demonstrating an ability to express approval or disapproval of others (3) awareness of the role of the representative and (4) a trusting relationship with the representative (Kerzner, 2011, p. 39). The RAA is also favoured as a model for its recognition of the 'shades of grey with respect to capacity' and the provision of a flexible arrangement in supported decision making (ibid).

Saskatchewan – Saskatchewan introduced 'co-decision-making' legislation in 2000 in which any 'legally-binding decision cannot be made by either party alone' (Carney & Beupert, 2013, p. 184). There have been few applications under this co-decision making law and it has been suggested barriers include: the cost involved in making an application to the court; a lack of public education about co-decision making; and most support of this form is provided informally (Surtees, 2010).

Yukon Territory – The Decision Making, Support and Protection to Adults Act (2007) is considered a well-conceived piece of legislation, for its provision of options ranging from supported decision making agreements, substitute decision

making, and guardianship (Kerzner, 2011, p. 55). Supported decision making arrangements can cover both personal and financial decisions and those that provide the support are known as ‘associates’. The Act clearly defines the responsibilities of the associate as: ‘(a) to assist the adult to make and express a decision; (b) to assist the adult to obtain relevant information; (c) to advise the adult by explaining relevant information and considerations; (d) to ascertain the wishes and decisions of the adult and assist the adult to communicate them; and (e) to endeavour to ensure that the adult’s decision is implemented’ (Schedule A, Adult Protection and Decision-Making Act, s. 5(1)). It also makes clear that guardianship should only be applied when all other forms of support have been exhausted (Kerzner, 2011).

Australia

Australian scholars have been at the forefront of supported decision making research and many of the empirical studies included have been conducted in Australia. In 2014, the Australian Law Reform Commission published a report detailing the needed changes to realise the principles outlined in the CRPD and introduced four decision making principles: (1) the right of all people to make and have their decisions respected; (2) to be supported to make decisions; (3) for supported decisions to be the ‘will, preference, and rights’ of the individual; and (4) the provision of safeguards as appropriate (Carney, 2015, p. 9). The guidance on these four principles would inform the appointment of either a ‘supporter’ or a ‘representative’ depending on the level of support required, thus acknowledging the continuum of support needs required in implementing supported decision making.

Addressing Barriers to the Implementation of Supported Decision Making

Carney & Beaupert argue that the root of the problem of implementing supported decision making is that it is ‘conceptually ill-defined’, leaving it open to multiple interpretations, and that the ways in which people are supported in decision making usually lies beyond the scope of the new CRPD-compliant capacity legislation (2013). Carney (2017) goes further to claim that the CRPD’s introduction of supported decision

making ‘has largely been a case of much talk and little real action’ (p. 18), while Arnstein-Kerslake, et al. raises concerns that supported decision making could become another bureaucratic tick box exercise (2017). The Code of Practice guidance is, therefore, critical in helping to develop the ways in which legislation is actioned, and supported decision making initiatives should be explicitly linked to the legal framework (Davidson et al., 2016). Other potential barriers to implementation include slow progress on legislation reform, high cost of implementation, the need for staff training, inconsistent practices, concerns regarding safeguarding, and a lack of involvement of people that require decision-making support in developing the supported decision making practices (Goldsmith et al., 2008; Ahmed et al., 2011; Hoole & Morgan, 2011; Carney, 2017). In addition to the institutional barriers to implementation of supported decision making, people with learning disabilities have also identified the following challenges: (1) adults with learning disabilities are often viewed as children; (2) a power imbalance exists between the supporter and supported; (3) confusion over differences between ‘mental disorder’ and ‘learning disability’ by supporters; (4) the need to balance protection against autonomy (and risk taking); (5) a failure to consider that different decisions may require different levels of support; and (6) the absence of a trusting relationship between the person being supported and their supporter (Jamieson, Theodore, & Raczka 2015; People First (Scotland), 2017).

Experiences of Supported Decision Making

A number of empirical studies have documented the experiences of individuals and supporters in the supported decision making process. One of the key findings has been that ‘decision-making is a dynamic and interactional process’ (Knox, Douglas & Bigby, 2015, p. 15) and that the relationship between the individual, supporter and the context is at the heart of the process (Knox, Douglas & Bigby, 2015; Jamieson, Theodore, & Raczka, 2016). Knight et al. (2018) explored the expectations of supported decision making in the narratives of 29 people with mental health problems in Australia. They found four main types of narrative positioning (the “Inward Expert,” the “Outward Entrustor,” the “Self-Aware Observer,” and the “Social Integrator”) which may overlap and change but this range of

positions emphasises the importance of trying to understand the subjective perspective of the person on the support they need for decision making at the time. Other studies have also discussed the relationship between the individual and the supporter, particularly focusing on the individual's feeling of powerlessness if there was not a good working relationship between them (McDaid & Delaney, 2011; Jamieson, Theodore, & Raczka, 2016; People First (Scotland), 2017).

Harding and Tascioglu's (2017) qualitative study explored the support available for the decision making of people with learning disabilities in England. They reported a range of very positive practice, especially for everyday decision making, and also found that "Difficult decisions were less well supported, overall, than everyday decisions or life choices. Most intellectually disabled participants reported being able to make some medical decisions, but often taking a supporter with them to appointments to help them in difficult interactions. Care professionals reported medical decisions often being made using the best interests framework under the Mental Capacity Act 2005, following multidisciplinary best interests meetings. Care professionals also reported being asked to sign consent forms on behalf of service users, or other inappropriate understandings of the MCA by healthcare staff. Frontline care staff often suggested that financial,

legal and medical decisions would be made by or through their managers, rather than being discussed directly with the disabled person. Legal issues associated with future planning (wills, advance decisions, power of attorney) were rarely discussed by intellectually disabled participants." (p.5)

Overall in the literature (Antaki, Finlay, Walton & Pate, 2008; Hoole & Morgan, 2011; ACT Disability, Aged and Carer Advocacy Service, 2013; Douglas, Bigby, Knox & Browning, 2015; Knox, Douglas, & Bigby, 2015; Kileen, 2016; Stavert, 2016), effective supported decision-making processes tended to:

1. include a commitment to the individual (including knowing the person well and respecting wishes for discretion or the involvement of additional parties);
2. follow support principles (including communicating in an open and non-challenging way, being honest, absence of undue influence or conflict of interest, and providing clear information in different formats);
3. clarity regarding the roles of the involved parties; and
4. adherence to relevant legislation; and
5. knowledge of a selection of flexible/ adaptable strategies.



Examples of good practice included: building supported decision making knowledge and skills of family members/friends; offering peer mentoring workshops for both supporters and people receiving support; ensuring that supported decision making is culturally sensitive; delivering supported decision making in partnership with independent advocacy services; and maintaining records of the steps taken in the supported decision making process (including the reasons for the decision, who was consulted, and what factors were considered) to help recall the details at a later date (Piffaretti, 2012; Kileen, 2016).

Many benefits of supported decision making have been identified, including increased personal autonomy and control, a clearer structure within families and professional relationships in making decisions and plans, and ensuring legal capacity to make decisions is respected (Chartres & Brayley, 2010). Research in mental health services has also found that when people feel they are listened to, even if they disagree with the outcome, they are less likely to feel dissatisfied with the service provided (McKenna et al., 2000; Galon & Wineman, 2010). It can therefore be concluded that supported decision making can have wider societal benefits through ensuring participation and recognition of citizenship rights, developing a more inclusive approach to the realization of disability rights, and developing a framework in which individuals are empowered to gain more control over their lives (Stavert, 2016).

Perhaps the most relevant study included in the review is the recent report by People First (Scotland), *Does it matter? Decision-making by people with learning disabilities* (2017), which was also funded by DRILL. The project's core research question aimed to explore whether supported decision making for people with learning disabilities in Scotland could offer a practical, safe and realistic alternative to substitute decision making (p. 5). Participants largely described making their own decisions positively and reported that it made them feel 'happy, good, powerful, proud, excited, in-control and independent' (p. 6). The report also found that 'substitute decision making occurred across a range of decisions, not just the most significant' and attributed this to a paternalistic view of adults who have a learning disability and the power imbalance between people who have a learning disability and others in society (p. 7). The

report concluded that it does matter to individuals that they can make their own decisions and that the 'opportunity to seek the views, ideas, opinions and advice of trusted people in coming to a decision is highly appreciated' (p. 9).

Conclusion of the literature review

The consensus from the papers included in this review is the need for more research on supported decision making and, in particular, more empirical studies. It is important that newly developed programs and legislative advances continue to build on our evolving understanding of supported decision making practices and that the research on which they are designed is robust and rigorously evaluated (Douglas, Bigby, Knox & Browning, 2015; Carney & Beaupert, 2015; Carney, 2017). There is still a great deal to learn about the practicality of different approaches to supported decision making and the experiences of the supported, supporters, and those tasked with enforcing supported decision making implementation measures. We must therefore gain a better understanding of how to overcome the identified challenges associated with delivering supported decision making in order to allow for the individual to have a greater say in how they live their life.



Overview of current guidance

As identified in the literature review, a range of guidance for supported decision making has already been developed across a number of different jurisdictions. As the main aim of this research project is to inform the development of guidance for the Northern Ireland context, some more detail of this existing guidance is provided in this section.

Options for Supported Decision Making to Enhance the Recovery of People with Severe Mental Health Problems (Kokanovic et al., 2017)

As part of this project in Melbourne, Brophy et al. (2017, p.8), based on their qualitative interviews with people with mental health problems, their families and mental health practitioners, identified four key enablers of supported decision

making. These four key enablers are shown in Figure 1 (Brophy et al 2017 p. 8)

The legal or rights-based mechanisms included: advance statements; nominated persons; second psychiatric opinions; and advocacy services.

Interpersonal strategies included the importance of connecting with the person, listening, problem solving, practical support, peer support and continuity of care.

Empowering people involved: strengths based approaches; facilitating access to information; providing opportunities to link with others and peer support; and encouraging self-advocacy.

Finally, management and leadership referred more to mental health services and emphasised the importance of: supervision and support for staff; using the available guidance on supported decision making; training and staff development; reflective practice; and the importance of recognising and rewarding good practice.



Figure 1: Enablers of Supported Decision Making

Support for Decision Making: A Practice Framework (Bigby & Douglas, 2016)

This project, also in Melbourne, focused on people with learning disabilities. Their project broke the process of supporting decision making into three elements:

- steps in support for decision making
- principles of support for decision making; and
- strategies for practice.

Figure 2 (Bigby and Douglas p. 10) summarises these elements.

Bigby and Douglas (2016 p. 16) summarise the main strategies in Figure 3.



Figure 2: Process of Support for Decision Making

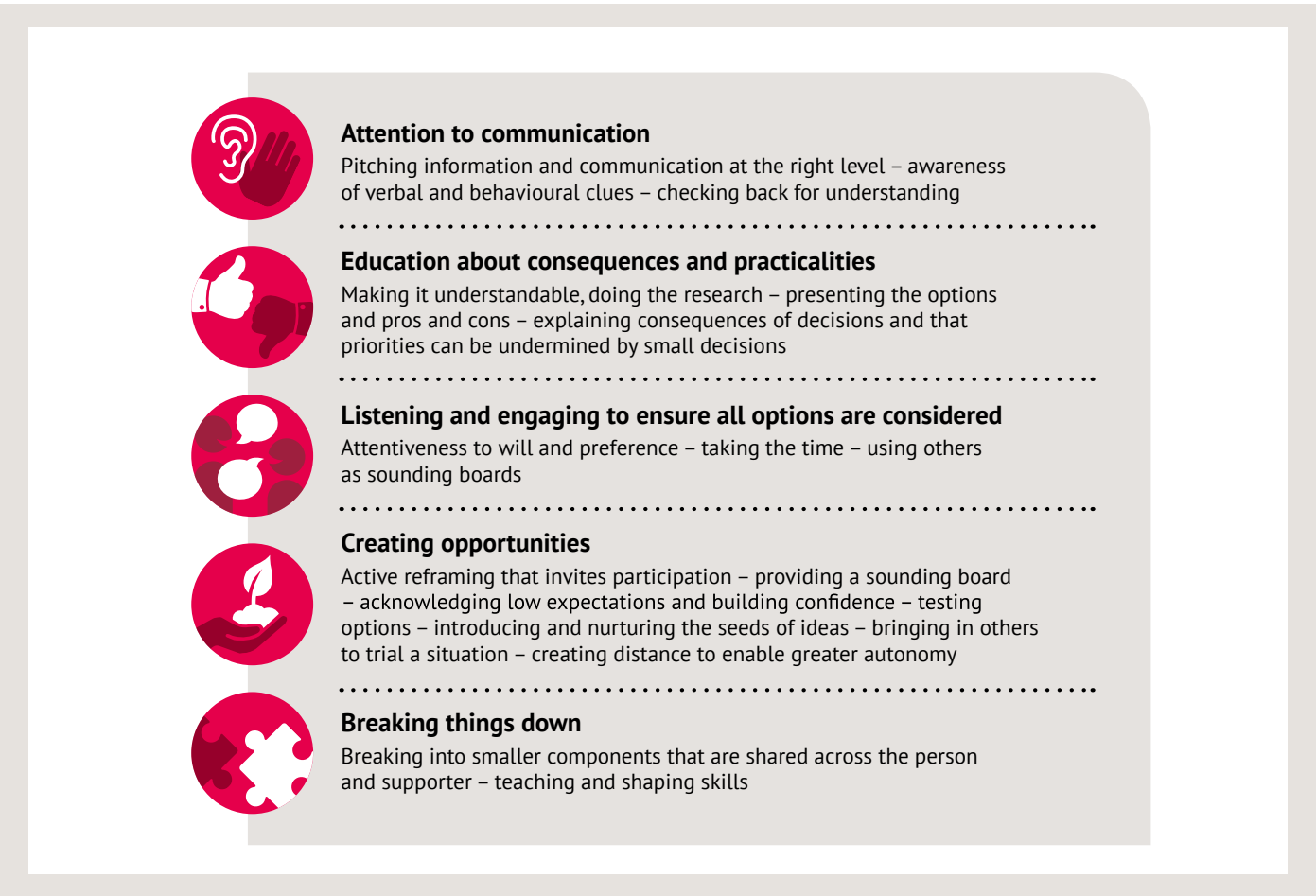


Figure 3: Strategies in Support for Decision Making

Mental Capacity Act 2005 Code of Practice (for England and Wales) (Department for Constitutional Affairs, 2007)

In the Mental Capacity Act 2005's Code of Practice, Chapter 3 provides guidance on how people should be supported to make their own decisions. It suggests the following questions should be explored:

Providing relevant information

- Does the person have all the relevant information they need to make a particular decision?
- If they have a choice, have they been given information on all the alternatives?

Communicating in an appropriate way

- Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
- Have different methods of communication been explored if required, including non-verbal communication?
- Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

Making the person feel at ease

- Are there particular times of day when the person's understanding is better?
- Are there particular locations where they may feel more at ease?
- Could the decision be put off to see whether the person can make the decision at a later time when circumstances are right for them?

Supporting the person

- Can anyone else help or support the person to make choices or express a view?" (pp. 29-30)

It provides further detail in each of these areas

including this guidance regarding time:

- Don't rush – allow the person time to think things over or ask for clarification where that is possible and appropriate.
- Avoid or challenge time limits that are unnecessary if the decision is not urgent. Delaying the decision may enable further steps to be taken to assist people to make the decision for themselves." (p. 36)

Mental Welfare Commission for Scotland's Good Practice Guide Supported Decision Making (Stavert, 2016)

This clear guidance also identifies the key elements of effective supported decision making arrangements. These include:

- Adherence to relevant legislative principles and human rights;
- Presumption of capacity and functional capacity assessments;
- Absence of "undue influence" and conflict of interest;
- Family involvement;
- Acceptance and use of support is in the individual's discretion;
- Clarity regarding support provider;
- Honesty;
- Options and alternatives;
- Allow for risk taking; and
- Record keeping.

It also, for the provision of support, highlights the importance of:

- Taking time;
- Building and developing relationships;
- Education and training;
- Choosing appropriate times and environments; and
- Specialist advice and information.



Assisted Decision Making (Capacity) Act 2015. A Guide for Health and Social Care Professionals (Health Service Executive, 2017, Draft for Consultation)

This draft guidance for the Assisted Decision Making (Capacity) Act 2015 in Ireland provides detailed information on how to maximise capacity and support decision making. This includes:

In some situations, health and social care professionals will have more time available to support people to make their own decisions compared to others. Even in emergency situations, however, every reasonable and practicable effort should be made to enable the person to make their own decision.

The following factors are important:

- Does the person have all the relevant information needed to make the decision, in a format that he or she can understand? This includes information about possible choices and options available if he or she fails to make a decision.

- Could the information be explained or presented in a way that is easier for the person to understand?
- Are there particular times of the day when a person's understanding is better, or is there a particular place where he or she feels more at ease and able to make a decision?
- Can anyone else help or support the person to understand the information or make a choice, for example, a relative, friend or advocate. It is important that such a person does not put pressure on the relevant person to decide one way or the other.
- Some people may never have made or taken their own decisions so they may need capacity building, in other words to be supported to 'learn' to make a decision. This may be the case for people with an intellectual disability living in a residential centre for most of their lives where all decisions were taken for them by staff. As they become used to making their own decisions and they grow in confidence, the support they require should reduce." (p. 21)

It also suggests some practical steps to maximise decision making when assessing

capacity:

Approaches to enhancing a person's ability to understand information include:

- Using clear, simple and concise language
- While there is often a 'core' amount of information that must be understood, it may be helpful to break down information into smaller sections and pausing to allow each to be understood
- Avoiding medical terminology and jargon
- Speaking slowly and at an appropriate volume for the person to hear you
- Using concrete examples relevant to the decision to be made
- Setting out the options and choices
- Being aware that many people have difficulty with numerical terms
- Repeating information and reiterating key points
- Pausing to check the person's understanding.

There are a number of approaches to creating the right environment to facilitate and support decision making. These include:

- Choosing the best time when the person is most alert and able to make decisions
- Choosing the best physical location if possible
- Minimising distractions

- Giving the person time and space to make the decision
- Being aware of any medication which could affect the person's capacity and considering delaying the assessment until the effects of the medication have subsided.
- Ensuring that all communication with the person is tailored to the person's individual personality
- Involving other health and care professionals with relevant expertise

The kind of support provided might include:

- Using a different form of communication (for example, non-verbal communication)
- Providing information in a more accessible form (for example, pictures, drawings)
- Treating a medical condition which may be affecting the person's capacity or;
- Having a structured programme to teach or improve the person's capacity to make particular decisions (for example, helping a person with an intellectual disability to learn new skills)." (p. 22-23)

Another important source of guidance that is currently being developed is the National Institute for Health and Care Excellence's Guideline on *Decision making and mental capacity*. It is estimated that this guidance will be published in July 2018



Methodology

The main method used to find out about people's experiences, the approaches to support used and what works was in-depth, qualitative, semi-structured interviews with 41 people with mental health problems and/or learning disabilities. Participants were interviewed by two members of the research team (a peer researcher and a member of the wider research team) and the transcriptions of each interview were analysed independently by two members of the team. Data was analysed with the help of the qualitative data software NVivo.

Peer research approach

A central aspect of the research was the involvement of four peer researchers, two with lived experience of mental health problems and two with learning disabilities. The benefits of the peer research approach include that the research process, from the development of the research questions, through data collection and analysis, to report writing is informed by those with lived experience (Biziewska and Johnston, 2010). This approach may also improve the engagement process with participants (Burns and Schubotz, 2009) and add to the impact of dissemination (Smith et al., 2008). It may also have some benefits for the peer researchers in terms of training, experience and empowerment (Burns and Schubotz, 2009).

The peer researchers were recruited through an open recruitment process by Praxis Care and Mencap NI. They all attended a 2 day training programme in October 2017 with content delivered by members of the research team at Queen's University (Davidson, McLaughlin, Montgomery). Content included: an overview of the research project (roles and responsibilities); introduction to research methods; interviewing skills; research ethics; managing difficult situations; self-care; analysis and report writing.

The training provided opportunities for role-plays and reflection to prepare the peer researchers for a range of potential scenarios during fieldwork.

Ethics

The research (and all related documents, such as, distress protocol, participant information packs etc.), was reviewed and approved by the School of Social Sciences, Education and Social Work Research Ethics Committee at Queen's University Belfast.

Participant recruitment

Research participants were recruited from Praxis Care and Mencap NI via the lead researchers in each organisation who acted as coordinators of the fieldwork process (Webb and Mulvenna, respectively). Participants were purposively selected to attain a range of experiences of supported decision making and to ensure a broad demographic range (i.e. gender, age, urban/rural spread etc). Participants were initially invited to take part in the study via phone call, by email, by talking directly with a staff member who was familiar with the study or by reading a letter and explanatory leaflet. The fieldwork coordinators or another member of Praxis Care and Mencap NI staff initially explained the aim of the research study and what level of involvement was required from the participants. The participants were invited to take part in an interview with one of the peer researchers (who was accompanied by another member of the wider research team who provided transport and support if needed) at a date, time and place which was convenient for them.

Data collection

Semi-structured, in-depth qualitative interviews were utilised to find out about people's experiences, the approaches to support used and what worked for them. Forty-one people with mental ill health and/or learning disabilities were interviewed between November 2017 and January 2018. All interviews were held in participant's homes/or in Praxis Care or Mencap NI facilities (including offices and independent living units) across Northern Ireland.

Prior to starting the interviews, a member of the wider research team (Webb, McLaughlin, Mulvenna, Montgomery) read the 'participant

information sheet' (PIS) (see Appendix 1: Participant Information Sheet) to the participant reminding them of the purpose of the study; why they were selected and what was required of them; explaining the boundaries of confidentiality and ensuring they were aware that participation was voluntary and that they could withdraw at any time. Written consent was provided by participants in the presence of the researchers. Easy read versions of the PIS and consent form were developed by Mulvenna, Owens and Norris (see Appendix 2: PIS Easy Read and Appendix 4: Consent Form: Easy Read). Some baseline data and monitoring information was also collected as part of the funder's external evaluation of the overall DRILL programme.

Prompt sheets were also developed (see Appendix 6: Prompt Sheets) by the research team to support the interview process. These prompt sheets acted as visual aids to present questions and possible responses in a clear and concise format.

Participants were interviewed by two members of the research team. The peer researcher

(Norris, Owens, Keenan or Falls) led the interview with support from a member of the wider research team (Webb, McLaughlin, Mulvenna, Montgomery). All participants provided their consent for the interviews to be audio recorded using a digital voice recorder. The interview was guided by a semi-structured interview schedule (see Appendix 7: Interview Schedule and Appendix 8: Interview Schedule: Easy Read) developed by the research team, international advisory group and following a review of the international literature. The schedule was structured around three key areas: experiences of making decisions, approaches to support and ideas for future support. Interview duration ranged from 15 minutes to 70 minutes.

Sample characteristics

Forty-one participants were recruited in total – twenty one from Praxis Care and twenty from Mencap NI. The age of the participants ranged from twenty two to eighty years of age with a mean age of forty eight. The majority of the sample were male (n=29, 71%).

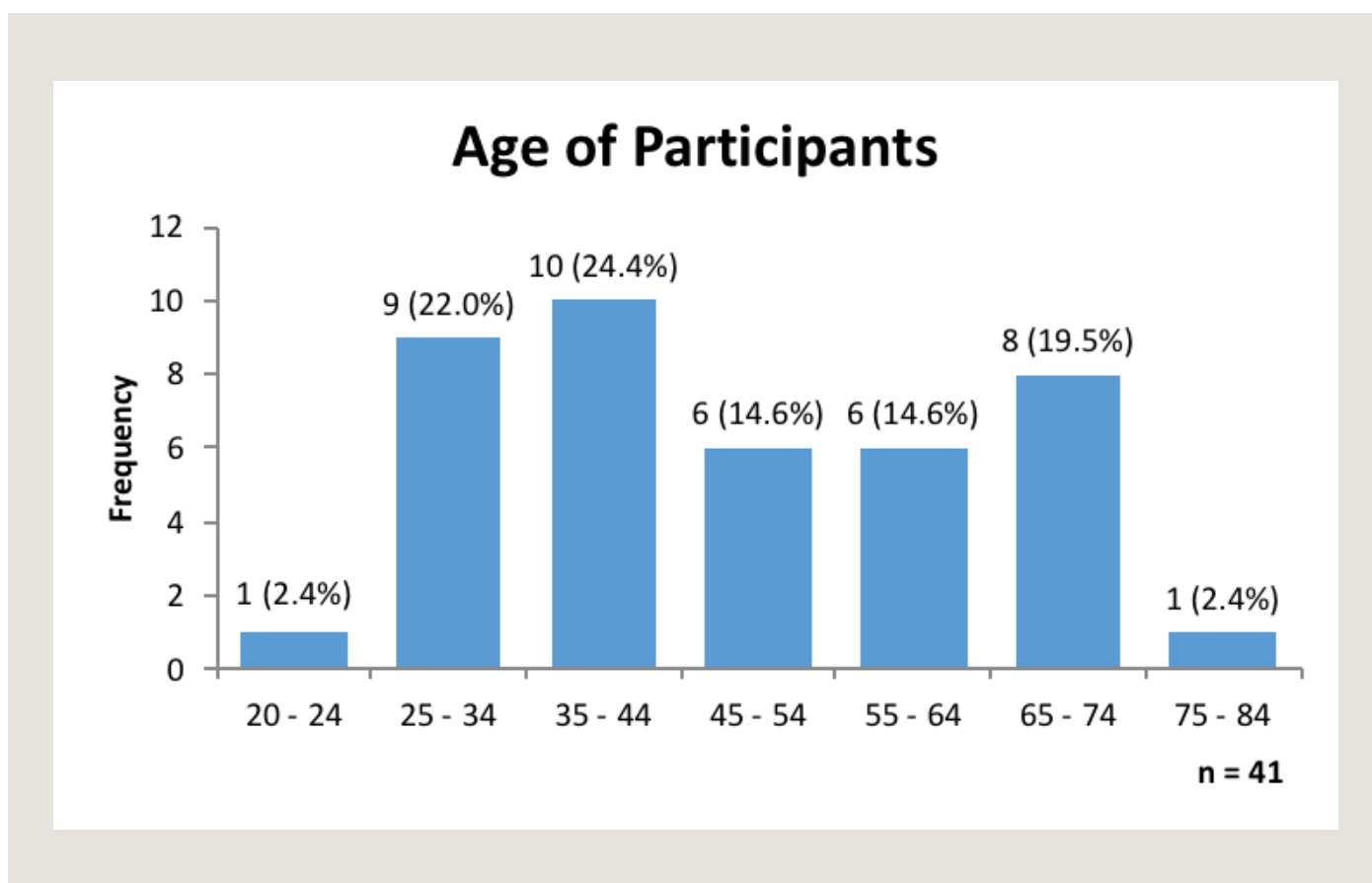


Figure 4: Age of participants

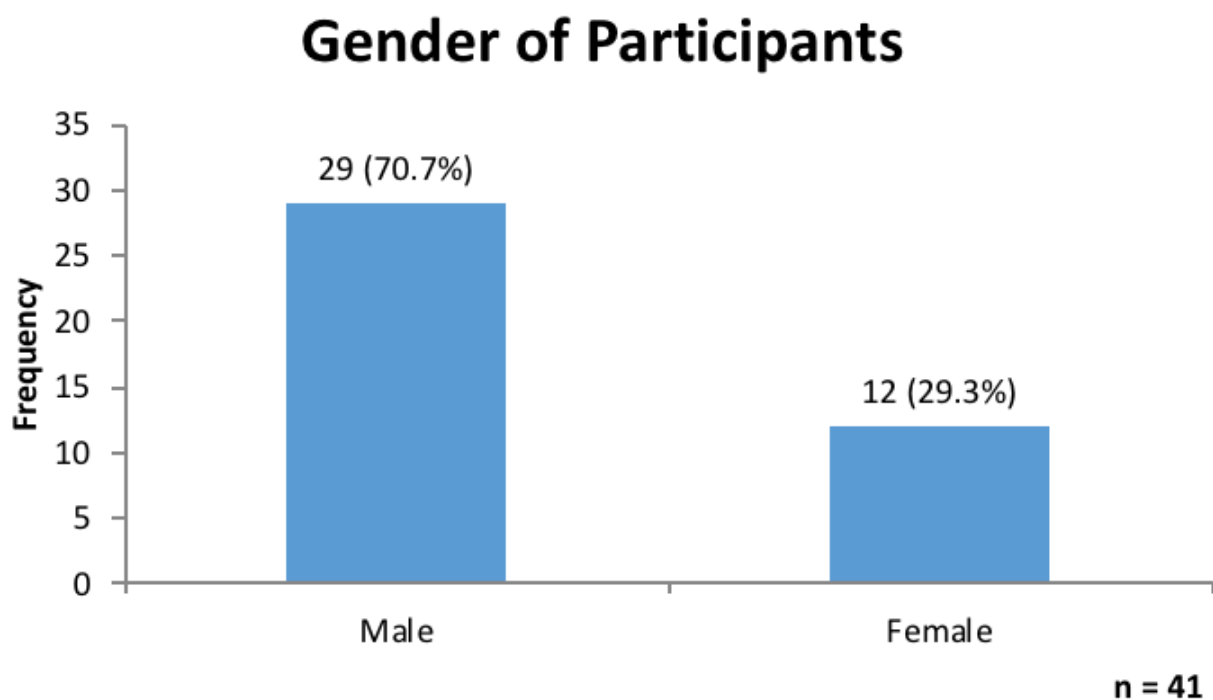


Figure 5: Gender of participants

Data analysis

Unique participant ID codes were allocated to audio recordings prior to transcription. Interviews were transcribed verbatim and transcripts were anonymised by the research team i.e. any identifiers (such as reference to names, addresses etc) were removed. An initial coding frame was developed by the research team selecting a sample of transcriptions, independently identifying codes and then discussing them. The data were analysed independently by two members of the research team (McLaughlin, Falls) using a thematic/content analysis approach facilitated by QSR NVivo.

In order to further increase the reliability and validity of the research findings the results of the data analysis were presented to all those who were interviewed at a participant workshop to ask for their feedback and comments on the emerging themes and the possible recommendations that could arise from them. A summary of the research findings was sent to all participants who were unable to attend the event.



Findings

Study themes are outlined in the following sections, falling broadly into two main areas:

1) experiences of decision making and **2) support.**

Experiences of decision making

Types of decisions: Every day, major and important recent decisions

A wide range of experiences of decision making were reported by participants providing insight into the types of decisions they make with specific reference to everyday decisions, major decisions and important recent decisions.

Many of the participants discussed in great detail their routine, health care and financial decisions. **Routine decisions** included those relating to shopping, housework, food, personal hygiene/ clothing and decisions on when to go to bed and day time activities. **Health care decisions** included decisions relating to physical and mental ill-health e.g. appointments, surgeries and lifestyle decisions (e.g. exercise; diet; cessation of smoking, alcohol/drugs). **Financial decisions** included having help with managing money for everyday decisions, making safe purchases, having receipts checked by staff etc. Participants also made references throughout the interviews to other important decisions they make including those relating to *education, housing, employment, their social lives, relationships and travel*.

In general, **everyday decisions** included those relating to finances, routine decisions, health, leisure activities, travel, education and employment. *Major decisions* were housing/living arrangements (e.g. moving out of supported living); health (e.g. major operations; lengthy stays in hospital; cessation of poor health behaviours e.g. smoking); substantial financial decisions (e.g. home renovations); relationships and family; education and employment; social welfare; holidays; and disagreements/legal disputes. Discussions around every day and major decisions often focused on the ease of decision making and the *information or support required*

to make the decision. The level of involvement of others/support in the decision making process was also evident from many of the accounts provided. Quite often **major decisions** were the result of a change in circumstances (e.g. moving home due to parents becoming ill/dying) or indeed impact on other areas of life (e.g. ability to manage medication; plans for new job/study when move out of supported living).

“Moving into my own home – so that was a big decision for me because ... I’ve always lived with my sister after my parents died, so that was a big decision to move out on my own and to make sure that I had enough support there to move out on my own – so that was a big decision for me, so it was.” (MEN006)

When asked about their most important recent decisions, participants often referred to education and employment; new courses or skills (e.g. learning to drive); spending time with family; health decisions (e.g. losing weight; abstaining from substances & gambling); housing (moving into independent living); social life and travel. Some felt that participating in the research study was an important recent decision.

“I suppose my decision to be in my job has been the most important decision in my life, and who I go out with and spend time with socially and having a bit of fun, who I spend time with.” (MEN013)

Experiences of having choices

Most participants felt that they had a good variety of choices in life:

“I would have plenty of choices” (MEN007).

Choices included routine decisions (e.g. cooking, shopping), health (e.g. medication), education and employment (e.g. having a couple of part time jobs, retirement decisions), finances, where to live (e.g. given a few options), spending time with family, relationships (e.g. getting engaged), leisure activities, going to church and holidays. Family members were often cited as those



who provided them with options. For some, the perception of having choices changed over time perhaps due to changes in attitudes of others.

“I’ve come to the point now and I’ve come to the doctors that I trust, the doctors now are more forward and more understanding, they will listen to you now, they will listen, if you feel the medication is not working you have a right to say that to the doctor now, years ago you hadn’t that right, you had no say in the matter, and that’s how forward it has come because it’s more open now with mental health, it’s more open with your sickness.....they’re more respectable now and they respect you” (PRA010)

However, some participants indicated that they had limited choices (e.g. in relation to work placements) and when choices were limited they felt unhappy, uneasy and under pressure. A minority of participants discussed their preference for fewer options and one participant argued one option was enough. However, the majority of participants preferred a number of options to give “more of a variety” (PRA008).

Feelings when making own decisions

Feelings when making decisions varied (and were often dependent on the type of decisions to be made and having support). There was a sense that many were relatively independent and happy to make minor decisions (e.g. shopping, clothing) but welcomed support when required e.g. managing finances, major decisions.

“No he doesn’t make the decisions for me, I just give him whatever I get a week, I give him so much money, he takes so much money out of it you know for my bills.” (PRA013)

“Money wise I am not confident about, like if I had invoices or bills that I had to pay I think I would need assistance from my father to be able to sort that out, but in terms of shopping and getting food for myself and like say this time of year getting stuff for Christmas I am actually happy enough to do that myself.” (MEN018)

Many reported a range of positive feelings including feeling ok/good/happy, comfortable, fortunate, independent, confident, proud, excited, rewarded and untroubled at the prospect of having to make a decision.

“I feel very confident that like if I have made my own decision and people accept it and then I would have felt I would have achieved something that hadn’t really been achieved before, and that I wouldn’t have not needed anybody else to go through while making that decision” (MEN018)

“I feel very lucky and very independent, because I know there is a lot of people who don’t have the capacity to make the right decision” (MEN013)

Some reported more negative feelings towards decision making “I don’t like myself making decisions” (PRA019), the reasons for which ranged from:

- confusion, indecisiveness (which may be determined by their health/mood/medication- “whenever my health goes down I can be indecisive, but when I’m ok, on better days, I can decide” PRA015);
- procrastination - “Sometimes they are hard like you know? Putting things off, putting that off, I’m always putting things off usually you know?”- PRA009); to
- sadness, fear and stress/anxiety - “Sometimes scared because I don’t really know... sometimes I don’t really understand...” (MEN006).

The accounts of negative feelings around decision making appeared to be resolved by getting support from others and having all the necessary information. One participant in particular anticipated her future feelings relating to a major decision and the support which will help ease the transition:

“I’m excited about it but when the time comes I might get nervous, I might get

anxious and everything else, and that is when the staff support will come in to sort of take some of the stress off me, so even if they put restrictions on me, they’re doing it just to keep me calm because I don’t deal with change very well. That’s part of my illness, but, you know, once I’m out and once I’m moved in with **** (name of partner) and we’re settled and we’ve got everything, you know, the way we want it, I think it will be good” (PRA001)

Factors that make decision making more difficult

Following on from the above section, feelings when making decisions were often interlinked with factors which can make decision making more difficult depending on the **type of decision to be made**, the **impact on others/others influencing/making the decision** (e.g. upsetting them, pressure from parents) and the **outcome of the decision** e.g. “if it turns out to be a good thing then I feel good about it” (PRA015). Other factors were:

- trying to encourage others to listen to/agree with/understand the decision/needs of the individual
- poor support (e.g. not having anyone to talk to/remind them to attend appointments, staff changes)
- not enough information (e.g. inconsistent advice, not understanding the decision, information presented in an unfamiliar format).

“I feel good but sometimes you can’t do everything together. I find that hard because you have to make a choice what you want to do, and sometimes when somebody wants you to go here and somebody wants you to go there, all at the same time, you have to make a decision and say – no, you can’t go and you have to let people down, and I don’t



like doing that, but I mean, I have to do it because you have to work out what's more important" (PRA003)

"I knew exactly what I wanted. The main problem was getting them to understand but I did know exactly what I wanted, there was no doubt in my mind what I wanted, and that I was pursuing the only course I could to change the situation and how it worked for me" (PRA004).

"If there was no one I could talk to I wouldn't know what, I would be afraid of making the wrong decision, so I would" (MEN007)

Time

Time pressure was cited by many as a particular challenge when making decisions. A number of accounts were provided including moving to a new home at short notice and being put under pressure by family, social workers and psychiatrists to make decisions with some suggesting individuals should be given more notice for making decisions (with notice depending on whether they are every day or major decisions). Important issues included having time to think about the question, time to think about the answer and accessing information and support while considering the decision. For others, time pressure was not an issue. Some participants indicated that they are cautious and take their time to make decisions and do not let others put them under pressure – "most things I just tackle on my own time and effort." (PRA004)

“I felt that I should have made that decision ... they (family members) did talk it over with me, but I felt that I was rushed into the decision.” (MEN017)

“I would be afraid to make the wrong one, if I need to make a decision quick I would need to try and find someone to help me to make that choice.” (MEN007)

“Bit of time and think it well over and then let it sit for a while – just time and no pressure. But ‘that’ mightn’t suit everyone but it does suit me. Time heals everything.” (PRA006)

“Or decisions that mmm.... That has to be made quickly – that’s confusing sometimes – because you have to think right on the spot and sometimes it’s hard to think, because you... if I do that there, what’s going to happen to this and that – so sometimes it’s very hard...” (MEN006)

Mental health

The **current state of health** may also make decision making more difficult. This particular sub-theme was unique to the participants with mental ill health. Their mood, deterioration in mental health (e.g. anxiety, hearing voices), using drugs/alcohol and the effects of prescribed medication were often cited as impairing decision making (e.g. spending money) with participants highlighting the need for support when feeling ‘unwell.’

“Well, when I get hyper I spend too much, far too much – like I would spend about £500 in a day when I’m hyper. So sometimes I have to go to the staff and say – listen, I’m spending too much money here and, you know, especially they know I’ll get bad with my mood and my moods start to fluctuate... they wouldn’t take control of my finances or anything, they leave that up to me,

but they would help me in the sense of budgeting, you know?” (PRA001)

I would hear voices all the time from morning to night. All the time, they do my head in. They would stop you making decision ‘cause they would be saying to me, “do this or do that or do different things.” (PRA017)

I would say when I’m well, I don’t have a problem if I have a decision to make no matter what it is. But when I’m not well, it would be a different story.” (PRA007)

When others have made decisions

When asked have others made decisions for them in the past, some participants indicated “No, because I don’t give them a chance” (MEN020) and “I don’t listen to them” (PRA005). For a handful, it simply was not an issue currently (or any longer):

“No, I don’t think so, not that I can recall. No I think they (services) are very fair minded like. Everyone is very decent like. They see my point of view as well as their own so it was all very fair minded.” (PRA006)

“Nobody makes my decisions now, I make my own decisions, for years and years people did make decisions for me.” (PRA010)

A number of participants discussed times when **others had made decisions for them**. Those who made decisions included family, social workers, organisations and health professionals (doctors, nurses). Feelings when others made decisions included confusion, unhappiness, uneasiness, annoyance/anger/agitation, feeling under pressure, stressed, nervous and anxious. Reasons for feeling this way included: “I should have been asked” (MEN015). Circumstances highlighted included decisions over living arrangements, health (e.g. treatment), education and finances.



“I feel my parents would have more experience.....they were the ones who had made their decisions throughout life for me....so they were a big influence in my life so I would feel that they’re the main decision makers in my life.” (MEN018)

“I don’t like people making decisions about me, you know too many decisions. I like to be involved you know?” (MEN017)

“I have also been in a psychiatric hospital up in **** (place name) with a learning disability and I had mental health problems, irrational thoughts and that, I didn’t like being in there, you know somebody making the decision how long I stay and that.” (MEN017)

Medication was a frequently cited example of ‘others making decisions’ (particularly among

the mental ill health sample). There was frustration around the lack of input into decisions on the prescribing of medication (i.e. amount/dosage) and issues with requests to reduce/stop medications being ignored. Decisions around changes to medication without consultation caused anxiety for some participants. In addition, the policies/procedures in hospitals/supported living/prisons for controlled substances caused particular distress for a minority of participants.

“I don’t like the fact that my methadone, my mother has to get it, the policy of the ***** is that they can’t look after a controlled drug, so my mother and father have to drive in and collect it and then drive in the next day and give it to me.....I would love the policy to be changed here that I can get it, you know that they could mind it in a cabinet or something or else I could mind it myself, I used to mind it myself before I came in here” (PRA011)

Others indicated they did not care, were happy/ felt good when others made decisions for them due to their decision making capacity and circumstances (e.g. in pain/ needing an operation; feeling vulnerable on leaving hospital) or, for the present at least, were happy for decisions to be made for them.

“I don’t mind because they’re there for support. At some point in the future I’d like to make those own decisions for myself.” (PRA003)

“It can make you a bit edgy yeah but you have to sit back and think just say to yourself they are only trying to do you good, family decisions you know.” (PRA014)

Perception of decision making capacity

Perception of decision making capacity was discussed by a number of participants which was dependent on the type of decision, illness or learning disability. Some spoke retrospectively about decisions that were made on their behalf, acknowledging that they did not have the capacity at the time. For one participant in particular, not having capacity made decisions easy for them i.e. saying no.

“I’m learning disability, I dunno right from wrong, you know what I mean?” (PRA021)

“I know I’m not right, I’m not fit to work and I’m not fit to socialise and I’m not fit to make some decisions for myself.” (PRA011)

“I suppose with my mum and my dad deciding what education I was going to go for. They would have made that decision there, but it worked out for the best so it did because I didn’t have the capacity.” (MEN013)

“All of a sudden put into a lock up, but at the end of the day I’m not going to run

down no doctors it was the safest place for me, at that time it was the safest place for me, then I understood, I did understand then but when I was told what was happening to me and what was happening to my body it was the safest place for me.” (PRA010)

“If it’s to do with my medication and the anxiety it’s easy for me to make a decision because I know that I’m not able to do stuff, so I just say no outright.” (PRA011)

Some felt that they did have a say in their medication. For others, there was an acknowledgement that they were unable to manage their medication at times in the past and they need for guidance/ have their medication monitored. Some participants reported that managing their own medication was useful/ satisfying.

“I used to get my monthly supply of tablets and I’d have them all gone in two days – take everything. And now like, whenever they are down at my house and they say, is your medication alright, I don’t have to show them but when I do show them they are all at the date you know.” (PRA008)

“Yeah I made decisions about medications, I said that I wanted to go on to certain medications and I agreed that I wanted to stay on medications because they were helping me.” (PRA011)

Decision making history

Some participants spoke about having a history of long-term difficulty with decision making (and making poor decisions) - “I’m not good at making decisions” (PRA012). Some queried the roots of such difficulty e.g. whether it stemmed from childhood; difficult relationships with parents; or lack of autonomy. Changes in decision making over time were also identified i.e. changes in ability to make decisions as they



got older; changes in priorities (e.g. spending money on substances in the past-particularly among the mental ill-health participants; not being able to manage medication in the past and poor relationships with family members) and more opportunities (i.e. more support nowadays) - “those options weren’t there for people with a learning disability, the way they are now” (MEN013).

“Well as I was growing up I wasn’t really that confident about sort of making decisions on my own, I sort of relied more on my mum and dad to make decisions for me, but as I went to secondary school and sort of learned some subjects in depth and sort of was preparing for work experience, I was more inclined to make my own decisions because I was planning on getting to live on my own and live independently, so I needed to sort of make my own decisions there and then, and you know some decisions have been very easy to make and some decisions that were very difficult for me to accept

and I did not go through with some of them decisions (MEN018)

“I would weigh the whole thing up. I would now ‘cause with age comes wisdom. I learnt my lesson and the older you are, you tread cautiously. It comes with age.” (PRA006).

Hindsight decision making

Regrets over decisions made in the past included how money was spent, living arrangements, friendships, education, medication, work related decisions and lifestyle choices (e.g. abuse of drugs and alcohol). Some demonstrated deep regret for decisions; others reflected on not having enough information at the time.

“One is when they wanted to change my medication originally, what they told me – if I’d known then what I know now? I would have said no to it straight away, and I wouldn’t have allowed it” (PRA001)

“I have actually made some quite bad



choices in regard to decision making and I have been trying to forget about some of those decisions and actually I have tried to get on with my life and every day and continue on every day without having to reflect on those kind of decisions that had sort of affected me.” (MEN018)

“I went to rehab a few times and I ended up in jail because of my decisions, I would decide to look after myself far better now and stay in these kind of conditions, stay away from drugs and look after my mental health, I want to look after my mental health so I don’t end up in bad positions like jail anymore, never again in my life will I end up there.” (PRA011)

Many participants, however, stated they had no regrets over previous decision making citing reasons such as being happy and confident with their decision making: ‘Yeah I was confident that I made the right choice of what I wanted to do.’(MEN007).

Support

The second main area of the findings is on participants’ experiences of and views on support.

Sources of support

Support was provided by a range of individuals, primarily family members but also work colleagues/managers; friends; housemates; key workers/support worker/carers/social workers/care and protection teams; mental health teams; health professionals (e.g. GP’s, psychiatrists, nurses, CPN’s, OT’s); organisations; educators; neighbours and other sources (e.g. drama groups, special Olympics, choirs). Participants also recommended that these sources should continue to provide support in the future (a wide support system where possible). Changes in circumstances (e.g. family illness/death) often impacted on the social support available and sources of support could be dependent on the decision to be made. For some it may depend on how they feel about needing support and whether they can cope. Participants also provided accounts of providing support to others. Some were employed in positions where they could help others and advocate on their behalf (drawing on their experiences). Overall, the value of support from family, colleagues and peers was particularly highlighted:

“The support that I got from my mummy and my daddy has been crucial to me and I wouldn’t want it any other way, and the support that I have with colleagues and friends throughout my life.”(MEN013)

“I was just taken out of the house and then put into hospital and was told nothing, nothing was ever told, what was wrong with me or nothing, I mean my mum would come to the hospital crying and all, I didn’t know what was going on and no one was telling anything because they ‘didn’t know’ you know.....I think they (family) should be with you ‘all’ the time.” (PRA008)

In general, participants seemed to be capable of actively seeking support where necessary e.g. approaching staff for advice/information. Some had concerns about not being assertive enough in asking for help- “Sometimes I’m afraid to ask for help in case they’re busy, or I want to save time, or I don’t want to cause a fuss.”(MEN017). Where support was unavailable, participants relied on other sources e.g. internet. The importance of support for family members was also highlighted: “When I’d been sick and my Mum used to ring for help for them – they said, this is your problem, you deal with it. That’s what she ever got told, you know, they wouldn’t help her.” (PRA001). Support required during periods of transitions was also highlighted and the impact this had on decision making- e.g. after major operations (getting back into a routine), upon release from prison (coping with being ‘institutionalised’) and upon leaving supported living or psychiatric care (e.g. learning how to manage own medication).

The qualities of a ‘good supporter’ were discussed by participants. In general, this was someone who was approachable, accessible, available and consistent; had a good relationship with the service user; similar interests; someone they could talk to; a good listener; acknowledges the service users perspective; showed empathy; was understanding; kind/caring; helpful; had good social skills; provided clear advice/information; was experienced/qualified (for their job) and knowledgeable (subject specific; knows the needs/behaviour of the service user); and

trustworthy, respectful and showed genuine interest in the service users life.

“People you have a good relationship with, people you can talk to. Not someone who’s going to stand there and go – this, that and that, and you do this, this and this. You don’t want that, you want somebody who can listen, understand your point of view, what the problem is and why there is a problem – and from that point on, information changed hands ... it’s more chance of being valuable, than just someone just ranting at you, you know?” (PRA004)

“Good support would be like, to be there for the person and for the person to know that you can phone them up or go and see that person whenever you need to see them. And if that person is not there, maybe to have somebody else there – so that you can call on to .”(MEN006)

Helpful support: how people could be supported to make decisions

The ways in which people should be supported to make decisions in the future included: consulting with the service user; inviting them to attend organisational meetings to inform policy/practice change; sitting on interviews panels when recruiting new staff; attendance at meetings on their progress (i.e. review meetings); providing them with adequate information in an accessible, clear and precise format, tailored to their needs; listening to their views via discussions/reviews (e.g. medication/treatment); treating them with respect; more staff and more time with staff.

“Talking it over with them, actually talking over in a review like with their service manager or the assistant manager and the social worker and whoever, I get a choice whoever I want at that review, and they could give me advice about that and say this is what I think, or what you think, and they ask how you would feel about it

and that's what I like, and I hope to get it like that if they agree, even though I don't accept everything." (MEN017)

Current helpful sources of support included practical, informational and emotional support. Practical support included management of medication; prompts or reminders (e.g. appointments), finance (e.g. assisting with banking, social welfare); assistance with routine tasks (e.g. filling in forms); documenting progress in diaries; seeking advice/expertise; securing employment/voluntary work and support in the workplace; showing service users what to expect (e.g. new accommodation, transport); securing housing near family members; tuition, education and learning support; technology (e.g. iplans); development of coping skills and knowledge; and social activities to 'get out of the house' (PRA009) (e.g. day centre).

"They have set up an iPlan on the computer and we've got an online calendar so they can put things in and we can put things in, the tenants that have the laptop can put things in the calendar so they know where we are instead of coming over all the time to check." (MEN007)

"My Manager she's very good at helping me with support and asking me how today went, do you need any support with things? So we both sit down once a week and run through what we've done or run through what we need to do next week, and then we would decide if we need some support there." (MEN006)

Informational support included advice on budgeting money (e.g. controlling spending when moods fluctuate); reading and explaining forms/letters to service users; advice on physical/mental health (e.g. what to do when feeling down); and tailoring information to meet individual needs.

"I think a powerpoint, because a powerpoint would sort of way point out and would guide them, for example say if someone who has a learning disability, who is struggling, he can't write or anything,

you could always put the powerpoint up instead of writing, you know put the likes of pictures up." (MEN019)

"That helps yeah, she can read it out for me or she can explain to me what's going on, it's easier to take it verbal." (PRA014)

Emotional support included peer support; encouraging service users to be independent; providing reassurance on decisions; and having a wide support network.

"Being able to talk to them about your feelings and your anxieties, and knowing that there is a good structure there, I like the sense of community around here and the few friends that I talk to." (PRA011)

"I just talk about the problems and talk about my sickness and talk about having a bad day, and it's great comfort to know that they're listening to you and it's great comfort when you get the response back, and they just keep yourself well ." (PRA010)

Should people always be supported to make decisions?

The reasons why people should be supported to make their own decisions were highlighted – freewill/independence- they are their 'own person' (MEN016) and can 'make up their own things in their own mind' (PRA013); it can make people feel good/happy; helps them to cope better; its important they are included in what's decided for them (and understand the pros and cons); can help them to make the right decision (when given advice/support); and makes decision making easier. The importance of safeguarding people with a learning disability was highlighted and other issues were identified such as the specific needs of the individual (and using the appropriate accessible information) and the type of decision.

"I think everyone has a right to their own independence, so they have a right to say if they wanted support with a decision." (PRA015)



“It’s not that they can’t make decisions for themselves, they just might need a bit of support with making decisions.” (MEN020)

“I think it’s important for people with a learning disability to have their own choices in life but be supported and be given the option, but obviously they do be to keep them safe too.” (MEN013)

“I think it’s important for people to be fully included in the decisions that’s made ... so it’s hard. So people are fully in control of what they’re doing.....because I don’t want people to go through what I went through. I like people to have enough information that they can make decisions about things.” (MEN006)

Participants did acknowledge that there may be cases *where individuals should not be supported/ others may have to make decisions* (or partial decisions) e.g. not having the capacity; not having enough support (e.g. no family members); when they have been admitted for psychiatric care/ mental health has deteriorated; emergency operations/procedures and self-harming. In those circumstances, those who could make the decision included family members and carers (while respecting the individual’s wishes). However, in general, there was a sense that individuals should be supported at all times, where possible. Others gave examples in line with poor decision making as opposed to not being able to make decisions e.g. listening to friends rather than parents or staff.

“They should be supported all the time, like you know. Obviously I would think, it would be the right thing to do just to support them all the time.” (PRA016)

“The family would make that decision, if I can’t make a decision I would count on family to make the decision.” (MEN007)

“When you’re mentally unwell, definitely they should take – not all of your say, but about 80% of your say off you, just until you get better, and then ... gradually build you back up again to where you were initially before you got ill.” (PRA001)

“There’s times when the doctors have to make decisions if you’re self-harming which I don’t myself and I’m glad they made them decisions because <name of participant removed> wouldn’t be here now if they didn’t make them.” (PRA010)

In summary there were a number of key themes from the findings:

- The need for a wide circle of support and recognition of inter-dependence
- Supported decision making as a dynamic process
- The need for a culture of listening
- The impact of values and attitudes to impairment and paternalistic practice
- The importance of trusted relationships built up over time
- Accessibility issues: accessible information, processes and additional time to make decisions
- Importance of supporting people with mental health and or learning disabilities to build their assertiveness and confidence to make decisions (and linked to this – the helpfulness of peer support and emotional support)

Discussion

This project provides insight into disabled people's experiences of the range of approaches provided to support decision making; what approaches work for whom; and what people's preferences are for support. Whilst variations in experience and preferences were evident in this study, the discussion will focus on broad themes that arose from the findings.

Decision making experiences

The participants in this study identified a wide range of experiences of decision making in terms of everyday decisions, major life decisions and important recent decisions. Whilst there was overlap in categories, in general, everyday decisions included those relating to finances, routine decisions, health, leisure activities, travel, education and employment. Major decisions often related to periods of transition, and included decisions about housing and living arrangements; health; substantial financial decisions; relationships and family; education and employment; social welfare; holidays; and disagreements or legal disputes. Important recent decisions, related to education and employment; new courses or skills; spending time with family; health decisions and decisions relating to housing social life and travel.

Many participants identified having a variety of choices in their life and it was noted by some that the opportunities to make choices had improved over the years. To a large extent the opportunity to make decisions was considered to be a positive experience, whilst the account of negative feelings associated with decision making was felt to be ameliorated by support and information. Participants identified three broad factors which could make decision making more difficult. These relate to the type of decision to be made, the impact on, or influence of, others and the outcome of the decision. The importance of relationship was highlighted in this context and included concerns around the pressure of trying to please too many people. Another significant factor related to the pressure of time. Participants identified that having time to

think about a question, time to think about the answer and access information and support while considering the decision, were important factors in supporting decision making. In this context, the value of developing assertiveness skills was evident.

It was also noted that participants' state of health was an important factor, particularly in relation to mental ill health. Perceptions of decision making capacity were also deemed to be important. Some participants perceived that, either currently, or some time in their past, they did not have the capacity to make decisions and had welcomed the input of others. Perceptions of capacity may however reflect unhelpful attitudes to disability. Finally, in discussing experiences of decision making, some participants described their personal history, reflecting on potential 'causes' of their difficulty in decision making and identifying behavioural patterns in how they made decisions. Moreover, some participants discussed regrets over decisions they had made in the past. These included issues relating to how money was spent, to their living arrangements, friendships, education, medication, work related decisions and lifestyle choices.

It was evident that decision making experiences were often viewed in the context of relationship; many positive aspects related to the support and empowerment received from others, whilst negative experiences often related to attitudes to disability.

Support

Participants identified a wide range of experiences in terms of the support they either needed or received in making decisions. Some decisions were made without support, some decisions were made with support from others. Support included the opportunity to access information, review pros and cons and get feedback from others. The central importance of family members in providing support in decision making was highlighted. The network of relationships and the interdependency within the network was also seen to be important. In addition to family support, support was provided by a range of individuals including: work colleagues; friends; housemates; educators and neighbours. The role of health and social care professionals was

also seen to be important, and included support provided by key workers, support workers, carers, social workers, GP's, psychiatrists, nurses, CPN's, OT's. Although there were some exceptions identified, participants seemed to be capable of actively seeking support where necessary. The qualities of a 'good supporter' related to characteristics of the individual, to the quality of the relationship and to the knowledge and experience held by the supporter. Thus positive personal qualities included being: approachable, accessible, kind and helpful, showing empathy and understanding and displaying good social skills. Characteristics of the relationship which were valued, included; sharing similar interests, someone they could talk to, a good listener, acknowledges the service users perspective, and showed genuine interest in the service user's life. Finally, the ability to provide clear advice and information, was experienced or qualified for their job and was knowledgeable was also valued. It is interesting to note that many of the qualities of a 'good supporter' related to the perceived value-base of the supporter, their genuine desire to help and their ability to take a partnership approach. This appeared to be given more weight than the skill and knowledge of the supporter.

Preferences

Helpful sources of support included practical, informational and emotional support. The issue of anxiety in decision making was raised here and throughout the findings, emphasising the importance of helping individuals to develop self-belief and confidence.

Practical support included both tangible interventions and empowering individuals to develop their own skills and knowledge to manage areas such as medication; attending appointments, assistance with finance, employment, voluntary work, finding accommodation and using transport. Informational support included advice on budgeting money, reading and explaining documentation, advice on physical and mental health and tailoring information to meet individual needs.

Emotional support included peer support; encouraging service users to be independent,

providing reassurance on decisions, and having a wide support network.

Some ways in which people should be supported to make decisions in the future were identified. These included: consulting with the service user; inviting them to attend organisational meetings to inform policy or practice change; sitting on interviews panels when recruiting new staff; and attendance at meetings on their progress (i.e. review meetings).

Finally, the reasons why people should be supported to make their own decisions were highlighted – and included the importance of promoting freewill, autonomy and independence; the positive value of decision making in helping people to cope better, in respecting their choice and in helping them to make the 'right decision'. The importance of safeguarding people with a learning disability was highlighted and arguably applies also to people with mental health difficulties.

Whilst there was a general sense that individuals should be supported at all times to contribute to decisions which affected their lives, participants did acknowledge that there may be cases where individuals should not be supported to make a decisions including when someone lacks capacity.

Conclusions

This research project has been a positive partnership between Praxis Care, Mencap NI, Queen's University Belfast, all the research participants, the International Advisory Group and the research funder, Disability Research on Independent Living & Learning (DRILL).

As part of the research project it was possible to further discuss the findings at an event for the participants and with the International Advisory Group. The following conclusions have therefore been informed by: the review of the literature; the findings from the interviews with participants; the discussion of the findings with participants and the International Advisory Group.

The key findings included:

- Decision making is a central aspect of people's lives. Participants discussed the positive role which decision making can have in their life but also how it felt when they are not supported to make their own decisions.
- Participants said there were three things that make decision making harder: the type of decision; the role of other people; and what the outcome might be.
- Time was consistently identified as a very important factor in making decisions.
- In terms of support, people said they would like: practical support including more accessible information; emotional support including someone to talk to; and sometimes the options to choose from.
- The peer researcher aspect of the project strengthened the research process and was valued by participants. This is an evolving area of research practice that needs further critical exploration of the issues involved.



Recommendations

The main recommendations are for how, in general, support for decision making should be provided but also specifically for how these findings might help to inform the Code of Practice which will provide important guidance on how people should be supported:

- Support for decision making needs to be individualised. The support needed depends on a wide range of factors including: the relevant information and how that can be communicated; the type of decision needed; who else is involved; what the possible options are; and what the outcome might be. The support needed will therefore vary across decisions, time and people so the support principle should be understood in a broad and flexible sense to reflect this variation and complexity.
- There was very little mention of existing, more formal processes of support such as advance decisions, crisis care planning and Enduring Power of Attorney. The new Act will introduce a positive, more comprehensive framework for these more formal processes but considerable efforts may be needed to promote public awareness and understanding of what these involve.
- Time was consistently identified as an important factor and it should be emphasised that if there is urgency to make a decision, what the cause of the urgency is and whether more time could be available.
- There are already a number of excellent sources for guidance for supported decision making, as highlighted in this report, and these international exemplars should help inform the operationalisation of the support principle.
- Although much of this project focused on the positive potential of support, the limitations and potential complexities of support should also be explicitly considered in the Code of Practice. Participants acknowledged that, in some circumstances, regardless of the support provided, it may be necessary for someone else to make the relevant decision. It should also be highlighted that what is intended to be support may, at times, move into undue influence, coercion and/or abuse.
- Participants highlighted that they bring considerable experience of support and were open to being further involved in discussing these issues. The Code of Practice will be open to public consultation and meetings, such as the participant event for this project, could be a very useful aspect of that consultation process.

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Appendices

Appendix 1: Participant Information Sheet

Participant Information

1. Study Title

Supported Decision Making: experiences, approaches and preferences



2. Invitation paragraph

You are being invited to take part in an interview to explore your experiences of decision making, the approaches you have experienced to support decision making and your preferences for how to be supported to make decisions. Before you decide whether to participate, it is important to understand why the study is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

3. Background

This project will explore, using in-depth interviews, how people with mental health problems and/or intellectual disabilities have, or have not been, supported to make their own decisions. It aims to provide an overview of the approaches to support that are possible and ask people what works for them. This will then be used to inform how people should be supported to make decisions in practice.

The project has been funded by Disability Research on Independent Living and Learning (DRILL), which is administered by Disability Action, and is being carried out by a partnership between Praxis Care, Mencap and Queen's University Belfast.

4. What do I have to do if selected?

If you choose to participate then you will be interviewed about your experiences and views of decision making. The interview will take place wherever you feel most comfortable, so it could be in your home, in a service setting or at Queen's. Two interviewers will be present and, if you give permission, the interview will be recorded.

Participation is completely voluntary – you can choose whether to participate or not. If there are many more people willing to be involved than can be accommodated then participants will be selected to provide representation of all ages and circumstances. By agreeing to take part in the interview, you will have the opportunity to express your views on how you have been supported to make decisions and how support should be provided in the future. The interview will last approximately one hour.

Even if you initially agree to be interviewed you can withdraw at any stage before or during the interview. After the interview the information you provided will be anonymized and cannot be withdrawn after that point but you can withdraw at any stage before then.

Withdrawing or deciding not to take part will have no impact on any services/supports that you currently receive.

5. What are the possible disadvantages and risks of taking part?

It is difficult to envisage any such disadvantages and risks as the focus in this research is on hearing your views on how support should be provided.

6. What are the possible benefits of taking part?

It is unlikely there will be any direct benefit to you from taking part in the study but we hope that it is an interesting experience and your views will inform how support for decision making is provided in the future.

7. Will my taking part in this study be kept confidential?

All information collected during the interviews will be kept strictly anonymous. If you have agreed to the interview being recorded, it will then be written down and the identifying information removed. The recording will then be deleted. No individual will be identified in the findings of the study although a list of the organisations who participated will be included in the report. The anonymised data will be available for other members of the Research Team and the funder to access and will be kept for at least seven years in a password protected computer in a locked office at Queen's.

If during an interview, the interview becomes concerned about your safety or the safety of others they will express these concerns to the relevant organisation.

8. What will happen to the results of the research study?

All participants will be invited to a presentation of the research findings. The research team will then also present the findings of the study to other audiences and will wish to publish the findings in academic/peer reviewed journals and present at conferences both nationally and internationally. In reporting and publishing these findings, your identity will always be kept anonymous and any quotes used from the interviews will also be anonymous.

9. Who is organising and funding the research?

The research team is:

Chief Investigator: Paul Webb, Research Manager Praxis Care.

Principal Investigator (Queen's): Gavin Davidson, Senior Lecturer in Social Work, Queen's University Belfast.

Peer Researcher: Aine Owers, Mencap

Peer Researcher: Barbara Norris, Mencap

Peer Researcher: Fionnuala Keenan, Praxis

Peer Researcher: David Falls, Praxis

Co-Investigator: Christine Mulvenna, Community Support Officer, Mencap.

Co-Investigator: Berni Kelly, Senior Lecturer in Social Work, Queen's University Belfast.

Co-Investigator: Lorna Montgomery. Lecturer in Social Work, Queen's University Belfast.

Research Fellow: Aisling McLaughlin, Queen's University Belfast.

Research Fellow: Rebecca Irvine, Queen's University Belfast.

The study is funded by Disability Research on Independent Living and Learning (DRILL), which is administered by Disability Action.

10. Who has reviewed the study?

The School Research Ethics Committee, School of Social Sciences, Education and Social Work, Queen's University, Belfast.

11. Contact for Further Information

Paul Webb 028 90727193 paulwebb@praxiscare.org.uk



Interview information



The interview is about how you make decisions.



How you are supported to make decisions.



What you like or dislike about the support you get to make decisions.



You can ask questions at any time.



It is **your choice** if you would like to take part in the interview or not.

Background



The interviews will inform how people should be supported to make decisions.



The project is funded by Disability Research on Independent Living and Learning (DRILL) through the Big Lottery Fund.



Praxis Care, Mencap and Queen's University Belfast will be involved in this project.

What do I have to do if selected?



Talk about your views on how you have been supported to make decisions and how support should be provided in the future.



The interview will last approximately one hour in a place that feels comfortable (like your home)

What are the benefits of taking part?



Your answers will inform how support for decision making is provided in the future.

Will my taking part in this study be kept confidential?



All information collected during the interviews will be kept safe with no names.



Interviews will be recorded, then be written down and the recording deleted.



If you or the interviewer are worried about something or at risk during the interview, we will pass this onto the person who supports you to keep you safe.

What will happen to the results of the research study?



They will be shared with government and other people who are interested.



Your name will not be used in the results

Who is organising and funding the research?

Some people you may meet on the research team:



Gavin Davidson
Queen's University



Paul Webb
Praxis Care



Christine Mulvenna
Mencap



Aisling McLaughlin
Queen's University



Aine Owens
Mencap



Barbara Norris
Mencap



Lorna Montgomery
Queen's University



Fionnuala Keenan
Praxis Care



David Falls
Praxis Care

If you have any further questions about this research or would like to talk further about it please contact Paul Webb on 02890727193 or paulwebb@praxiscare.org.uk

CONSENT FORM FOR INTERVIEW

Title of Project: Supported Decision Making: experiences, approaches and preferences

Name of Principal Investigator (Queen's): Gavin Davidson

Name of Researcher:

Please tick box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my use of services being affected. ☐
3. I understand that if I withdraw from the study, any information already collected and anonymized will be retained in the study ☐
4. I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data. ☐
5. I agree to the interview being audio recorded. ☐
6. I agree to the use of anonymised quotes from the interview. ☐
7. I agree to take part in the above study. ☐

Name of Participant

Date

Signature



Consent form for taking part in the interview

Please tick box if you agree



I have read and understand the information sheet	
I have had the opportunity to ask questions about the interview	
I know that taking part in the interview is my choice and I can leave at any time	
If I decide to leave the interview, I know that any information already collected will be used in the study	
I understand that the researchers will hold all information and data collected securely (except as might be required by law)	
I understand that the researchers will make sure that my name is not used in the study	
I give permission for the researchers to hold relevant personal data	
I agree to the use of my quotes during the interview without my name being used	
I agree to the interview being audio recorded	
I agree to take part in this study about decision making	



Participant name: _____

Date: _____

Researcher name: _____

Supported decision making - experiences, approaches and preferences

Distress Protocol

Pre Data Collection

- The researchers will explain the areas that will be covered in the interview and be mindful of the potentially personal and emotive nature of the interview.
- The researchers will be ready to respond with sensitivity and compassion to any expressions of distress.
- Participants will be reminded that they can choose what and what not to speak about in the interview.
- Participants will be reminded that they can ask for a break in the interview process.
- Participants will be reminded that they can end the interview at any time.

Stage 1 Initial response

- If a participant becomes distressed during the interview, they can discuss their concerns with the researchers conducting the interview in the first instance.
- The researchers will provide immediate support and will ask the participant if they need to take a break from the interview or stop the interview if required.

Stage 2 Review

- If the participant feels able to continue with the interview, resume interview (and upon completion, conclude the interview with 'Stage 4: distress debriefing').
- If the participant feels unable to continue with the interview, go to 'Stage 3: further response'.

Stage 3 Further action

- Discontinue the interview.
- The researcher will determine the nature of the service user participants' distress and provide further immediate support.
- If the participant is experiencing distress but is not deemed to be at risk to themselves or others, the participant will be encouraged to speak with either their GP or a member of the direct care team in their service for further advice/support. Or the researcher will offer, with participant consent, to contact either of these services on their behalf.
- If the participant is deemed to be at risk to themselves or others the researcher will inform a member of the service immediately for further advice / support.

Stage 4 Debriefing






For all participants who exhibit distress during the interview process:

- The emotive nature of any aspects of the interview will be acknowledged.
- The researcher will ask the participant how they are now feeling.
- The researcher will ensure the participant feels safe and able to go about their day.
- The researcher will provide information about potential supports and encourage the participant to contact their GP or their service if they experience further episodes of increased distress in the hours / days following the interview.






Everyday decision making examples

	What clothes you wear
	What you eat
	What time you go to bed
	How to spend your own money
	When you do your cleaning/laundry


Major decision making examples

 <p>My House</p>	Where you live
	Having a job
	Having a relationship or getting married
	If you can spend your money on something that costs a lot of money
 <p>Hospital</p>	Going for an operation in the hospital

Feelings

	<p>Happy</p>
	<p>Sad</p>
	<p>Confused</p>
	<p>Angry</p>
	<p>Stressed</p>

Things that might help you make decision

	Give me time
	Talk to me and make sure I understand
	Staff
	My family
	My friends

Semi-structured interview schedule

Before starting the interview please provide a clear introduction of your name and role – participants may be particularly interested in the role of the peer researcher so please do take some time to explain this and discuss if need be.

Please also go through the participant information sheet to ensure the person is aware of what is involved and then ask them to complete the written consent form if they are willing to participate.

Introduction to the questions – we're interested in finding out about how decisions have been made in people's lives. We want to explore how people have been supported to make decisions. We also want to try and find out what has worked well for people and what has not been so helpful. We're also interested in any ideas you might have for how people can be supported to make decisions.

Areas to explore:

Your experiences of making decisions

- **Please tell us about your experiences of everyday decision making (routine – including health, welfare, financial). Prompts – provide examples, what information/support did you need, were other people involved**
- **Please tell us about your experiences of major decision making (where to live, who to go out with, education, employment, serious health, welfare and financial). Prompts – provide examples, what information/support did you need, were other people involved**
- **How do you feel making decisions?**
- **Do you usually feel that you have a range of choices? Please ask for examples**
- **Any examples of decisions you've made which you now might approach differently?**
- **Are there times when other people have made decisions about your life? Please give examples. How did you feel about that?**
- **What have been the most important recent decisions in your life? Did you make them?**

Approaches to support

- **What support has been helpful for making decisions? Prompts – examples of support – information, taking it over with friends/family, advice from professionals**
- **What makes making decisions more difficult? Prompts – examples of barriers – uncertainty, lack of choice, impact on others**
- **Please tell us about anything else that might be important in making decisions. Prompts – timing, stress, pressure**

Ideas for future support

- **Should people be supported to make their own decisions? Why?**
- **Are there any circumstances in which people can't or shouldn't be supported to make their own decision? For example, in an emergency and/or, if a person, even with support, isn't able to make the decision**
- **Any ideas about how people should be supported to make decisions? Prompts – who should provide support, what would good support be like, what would a good supporter be like**

DRILL Peer Researcher Guidance Notes



Hello my name is _____

I am a peer researcher for Praxis Care



It is my job to ask you some questions about how you are supported to make decisions



Is that ok?

Thank you very much for agreeing to take part



I just want to remind you that this interview will be recorded, are you still ok with this?



My colleague Aisling will just go over a few things with you before we start

Aisling to complete: Check consent to participate

Introduction



We are interested in finding out about how people with mental ill health make decisions



And how they have been supported.



We want to try and find out what has worked well for people and what has not been so helpful.



We're also interested in any ideas you might have for how people can be supported to make decisions.



If you have any questions during this interview, please ask me.

Are you ready to start?

Interview Questions

Question 1:

- Can you tell me about your experiences of everyday decision making?

(see prompt sheet with pictures)

- What information or support did you need?
- Were there other people involved?

Question 2:

- Can you tell me your experiences of major decision making?

(see prompt sheet with pictures)

- what information or support did you need?
- were other people involved?

Question 3:

- How do you feel when you make your own decisions?

Question 4:

- Do you usually feel that you have a range of choices when you make decisions?
- Can you give me any examples of a time when you had to make a decision and you had choices about that decision?

Question 5:

- Do you have any examples of decisions that you've made which you now might do differently now?

Question 6:

- Are there times when other people have made decisions about your life?
- Can you give me any examples?
- How did you feel about that?

Question 7:

- What have been the most important recent decisions in your life?
- Did you make those decisions?
- Who helped you to make these decisions?

Question 8:

- What support has been helpful for you to make decisions?

Question 9:

- What makes decision making more difficult for you?

Question 10:

- Is there anything else that you think is important when you are making decisions. Prompts – timing, stress, pressure

Question 11:

- Do you think people should always be supported to make their own decisions?
- Why?
- Are there any times that you think people should not be supported to make decisions? For example in an emergency or if a person isn't able to make the decision

Question 12:

- Do you have any ideas about how people should be supported to make decisions?
- **Prompts – who should provide support?**
- **what would good support be like?**
- **what would a good supporter be like?**

Thank you for taking part in this interview, do you have any questions?

Aisling do you have any questions before we finish?

Thank you very much.



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